National Cancer Institute

caBIG cancer Biomedical Informatics Grid®

Building a Collaborative Biomedical Network

Question and Answer Session from the caBIG® 2010 Annual Meeting
Tuesday, September 14, 2010

Ken Buetow, Ph.D.
Again have given us very provocative thoughts as to how to move the agenda forward. I'll start since we have people lined up right away. Tom? Please introduce yourself and institution so we all —

Question 1: Tom Castelvan
My name is Tom Castelvan, University of Iowa. I am an Engineer, I work with a lot of subject matter experts and I think that the tension created by this panel is awesome. I have to push back just a little bit on something, I was fascinated by Ken's description of this Facebook and Wikipedia-style patient directed record. And having been involved in a number of really large molecular studies, genome-wide association, deep sequencing, I can tell you the precise definition of phenotype is really critical, you can waste an enormous amount of money on studies. We've done thousands of symptoms and come up with very little signal for every thought we had very carefully [inaudible] disease. And I guess I just like to maybe hear Ken's comments about how to curate because I think you end up with a bunch of Wikipedia style data. How do you envision that happening?

Ken Buetow, Ph.D.
I'll give one technical answer to this first that has a lot to do with the underpinning of how we actually manage most of our caBIG® data, and that has to do with structured information representation. So even though those forms had the look and feel of a Wikipedia or unstructured framework, this still uses the formal discipline of data curation, ontologies, vocabularies, and other components so that the information is structured.

The second of piece of what we found is that, in fact, especially in cancer situations, it's amazing actually how more accurate the patient's knowledge of their disease is than at times the indirection that comes through the electronic infrastructures or the research infrastructures where somebody else has had to ask somebody what their disease was. Now I'm not discounting the importance of going back for detailed studies to primary information sources. But what's interesting is those of us who actually quite commonly work and actually participate in the health arena, how commonly all my medical history actually is transmitted into the system through me, the patient, who's had to actually annotate on a clipboard or something else a whole array of stuff that then somehow gets into the medical record as having a validity now that it's in the medical record that it didn't have when I actually wrote it down on a clipboard to begin with. But I know my colleagues here actually have strong —

Susan Love, M.D.
Well, I was going to say the same thing. As a physician who's filled out millions of medical records, to think that that's the gold standard is just baloney. I mean, half the time we're doing it at the end of the day. You can't remember whether it was the right or left side and you don't really care. And the patient cares a lot more. And so I think this notion we have that the—and even radiology reports and pathology reports are not any more accurate. They're still being built by people and often people who are even less invested in having it exactly right than the patient would be. So I think the myth that—there's this myth out there that somehow doctors are doing—and the trouble with electronic medical records, it doesn't make it any better because sometimes it limits your choices of how to put the information in and so you pick the least bad choice as opposed to the accurate choice. So I think we need to be careful about really giving more power to the medical records than to the public. I think the public is probably more accurate.

Ken Buetow, Ph.D.
Other—no? Deb?

Deborah Collyar
Ditto.

Ken Buetow, Ph.D.
Excellent. And, again, just to finish my—the point, and if it wasn't clear, is what we would try to argue in this framework is that both sides are incomplete. So the systematic piece that's part of the traditional system has unique assets that are immensely important to be captured and brought into the system. The structured information around labs, all of the highly-precise information that comes from other components we really need to flow into this. On the other hand, there are unique perspectives and insights that come from the patient-centered view of this. And if we're not capturing those, we're also not capturing the full manifestation of phenotype. So I think it needs to be both.

Question 2: Betty Tranowski
Hi, I'm Betty Tranowski from NCI. Thank you all for just really wonderful presentations and getting us all kind of awake and juiced up this morning.

So you all touched on the challenge of the dialogue of communications between physicians, researchers, and advocates. But I think none of you touched on what I consider a really fundamental problem and so I'm kind of waving the flag for the researchers so they don't really have a bad name, maybe at least not in my heart. And that is their challenge is to get those grants funded, whether it's peer reviewed by the government or a non-profit agency. So the peer review process can be very brutal as I'm sure you're all aware. And I think it's a challenge that you might want to consider as to how—help the researchers if they're going to incorporate some of the needs of the patients and the physicians, how to incorporate that into their grants so they will funded, so they're not triaged, so they're not said, well, that's just soft science, ding. And that's a real problem. Do you have any comments?

Susan Love, M.D.

Well, one of the things in the breast cancer advocacy movement that we've done from the very beginning in the early '90s is when we increased the funding for research was to demand that advocates were on the peer review. So, for example, in the DOD breast cancer research program, there are advocates in the—as a member of the peer review commitments as well as the integration committee and all the way through to try to get that voice in. And it does make a huge difference in terms of—not just in terms of what's relevant to people getting more likely to get funded but even a little bit fairer peer review and less a chauvinism that sometimes happens in the peer review process. So I think that's one effort that's been going on for a while in breast cancer, and I think it's metastasized into other diseases and cancers as well.

Thomas P. Sellers

I can tell you I'm familiar with the American Cancer Society's research program. And when I was working with them in New England, one of the things we did was we actually did separate fundraising in order to fund grants that were not funded by the peer review folks that would otherwise not have been funded but may have been interesting and unique. So part of the answer is you really need to identify ways to set aside pots of money that are targeted to the riskier or the unusual types of studies that may come out of a peer review process. And if someone identifies them as being something that might be just really interesting to do, that you can do that, that's going to get harder to do, especially in a federal environment where they're already talking about across-the-board five percent cuts in the 2012 budget. But to the extent that either private organizations who are raising money for research can do more of that or you can start to think about whether there are ways within NCI to set aside some funds for that type of activity, that's the way some of that type of innovation is going to happen.

Deborah Collyar

And to tackle the big funder which is NCI, there are—the complementary programs to that may help with some of the newer ideas, but there are also patient advocates that are being put on to more and more of the peer review panels. And there may be more emphasis that needs to be placed in their training and discussions with them on how to make sure that these elements aren't dismissed or cause for not funding grants but rather causes for funding grants.

Ken Buetow, Ph.D.

Yes?

Question 3: *Fred Loney*

Hi, Fred Loney at Oregon Health Science University. I think it's great that the panel reminds a roomful of technologists that data is not the answer, that patient end results are the answer. And my question actually was along the same lines as the previous question or it seems to me that there are aspects of the grant process, the academic process, and researcher intellectual property that militate against that. Unvalidated biomarkers come to mind. Since you addressed the question of the

grant process, do you have any suggestions regarding either the academic process or research or intellectual property that would facilitate patient involvement and outreach?

Susan Love, M.D.

I think the academic process really goes and the, quote, research, enterprise goes against finding—is a deterrent to finding really big answers. We used to have physician scientists where you found a problem in the clinic, you went to the lab, figured it out, and you came back. Think Pasteur or something. Now you can't do that; it's impossible to be an expert in both. And so what happens is you have scientists coming up with things and then looking for a clinical place to put it. And technology being developed and then looking for what can we do with this in the clinic as opposed to taking a clinical problem and trying to figure it out. And then you've got to get tenure so you've got to get grants fast and so it's faster to use rats than people.

One scientist said to me, I said, "Why don't you do this research on people?" "Well, women are too messy." Rats we can control. We control what they eat. We can control their genes. It's nice, pretty science. And it is. It just doesn't help the people since rats don't get breast cancer. We have to give it to them in order to study it. And so we know a lot about breast cancer in rats, but it hasn't really all translated into—very little—some of it but not a lot has translated into really changing anything in the disease in people.

So I think we really need a whole system overhaul or revolution, and I'm hoping that getting more of the voice of the public in here will help to do this. But right now the goal is to get grants and to get tenure and it's not really to solve problems, clinical problems.

Thomas P. Sellers

I was just going to say I think that it really is very difficult to influence the academic setting and the kind of sets of incentives that are endemic to that setting. And what's more likely to happen is, to the extent that outside organizations, other non-profits, patient portals, the Army of Women begin to generate results in a sense outside that closed system, folks will want to buy in. And that's how that change is going to begin to come about but it's going to take time and it'll be a difficult process because, like you say, rats are easy.

Ken Buetow, Ph.D.

Last question.

Susan Love, M.D.

And you can control them.

Thomas P. Sellers

Yeah, you can control them. You can't control men or women.

Ken Buetow, Ph.D.

Last question.

Question 4: *Virginia Hatrick*

My name is Virginia Hatrick. I'm one of the caBIG® patient advocates as well. And like the panel, I'm also an almost 20-year veteran. Several years ago, actually 19 years ago, I first became a patient advocate as a clinical advocate, and Deb and a few hundred other of my closest personal friends made me into a research advocate. But the thing that really drives me for both of those is my friends are dying and I don't like that. And your friends are dying and you shouldn't like that either. So one of the things that I think that we can all do together is try to get researchers to understand the importance of all of us working together instead of everybody going off and doing their particular thing, whether it's getting grants or being a clinical advocate, being a research advocate, being a legislative advocate, whatever it is that we do. I didn't do advocacy because that's my academic training. I did advocacy and I do advocacy because it helps my friends.

Ken Buetow, Ph.D.

So I think that's a very outstanding place for us to break this morning's session. I think it's exciting to hear the changes that are afoot. And I think actually to connect this morning's plenary session with yesterday's is I think what we hear is a need for us to really think of new ways. And if we want to engage in disruptive innovation, we actually recognize there's going to be need for new organizational models, new ways for us to interconnect groups that have as common goals the attack on cancer in a manner that actually transforms how we approach this disease. I think information technology, as has been heard, is an important prerequisite to that activity but certainly is not the solution in and of itself. And I think what we saw this morning and connected with yesterday is a rising tide of groups interested in taking a different look at the problem.

So with that, we'll break. We will reconvene into our next sessions in about 15 minutes. So thank you all for your participation this morning, and please attend—I look forward to seeing you all later this afternoon at the award ceremony. So thank you very much and thank you to the speakers.

Speakers:

Ken Buetow, Ph.D.
NCI Center for Biomedical Informatics and Information Technology (NCI CBIIT)
Susan Love, M.D.
Susan Love Research Foundation
Thomas P. Sellers, MPA
National Coalition for Cancer Survivorship
Deborah Collyar
PAIR: Patient Advocates in Research and caBIG® Patient Advocate